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Commissioner's Message

ADD's International Support and Collaboration:

Wade F. Horn, Ph.D., HHS Assistant Secretary for Children and Families, (below, far left), along with Patricia Morrissey, Ph.D., (fifth from left), Commissioner of the Administration on Developmental Disabilities (ADD), met on Thursday, June 4, 2004 with this group of Iraqi citizens who were victims of torture and amputation under the regime of Saddam Hussein.



Discussions centered on U.S. services for persons with disabilities and possible future collaboration with the people of Iraq. The Iraqi gentlemen shared their concerns about and interests in civil rights and advocacy for individuals with disabilities.

The visitors were especially interested in videos, CDs and DVDs that highlight the abilities of individuals with disabilities participating, living, and working in community settings. If able to obtain these audiovisual materials, one of the gentlemen, who works for an Iraqi television network, will secure Arabic voice-overs for videos, CDs and DVDs. They thought such media immediately useful in shaping positive attitudes about Iraqis with disabilities, creating job and business opportunities for them, and increasing the likelihood that they would be included in

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community activities. The audiovisual materials would also serve as models in the future for Iraqi-produced media on these themes. Thanks to the many grantees who have already submitted their VHS and DVD materials, ADD will be able to select those materials that most closely address the specific concerns of our international visitors.

Monitoring and Technical Assistance Review System

MTARS

The purpose of the MTARS is to capture how grantees impact the lives of people with developmental disabilities. During an MTARS, the review team will look at network collaboration, accountability, compliance, organizational structure, technical assistance, and best practices. Recently, the MTARS had been broadened and revised based on the changing needs of our Government, ADD's reporting requirements and needs, and grantee feedback. ADD Update presents this special section on the MTARS to help further the understanding of changes, additions, and improvements made, and to offer suggestions on how to make an MTARS run smoothly.

MTARS Compliance and Organizational Structure Checklists

The MTARS Compliance and Organizational Structure checklists were developed to enhance communication between the MTARS team and the ADD grantees. Members of the Compliance/Governance subgroup determined that while grantees may demonstrate compliance with the DD Act there are systems that must be in place to ensure that the grantee organizational structure is able to implement the Act. Thus, two checklists were developed listing the DD Act citation that corresponds to the respective items. In developing the checklists, the subgroup reviewed several existing checklists as well as self-assessments in use by ADD grantees. The checklists are designed to serve as self-assessments for the grantees and note-taking tools for both the grantee and the MTARS team members. Below is a representation of the checklists that includes a compliance item for a State Council. The Ref Doc column is used to list the document source that demonstrates compliance (i.e. PPR, State Plan, meeting minutes). The three "Comments" columns provide space for the grantee or the MTARS team member to provide any specific information prior to the visit, to take notes during the visit, or to indicate any post visit concerns. If grantees utilize the checklists to provide information to the team prior to the MTARS visit it is anticipated that it will reduce the on-site time necessary to do document reviews. Comments thus far indicate that the self-assessment format is useful to the grantees and will help to improve the pre-visit communication of the grantee and the teams. Consequently, more time will be available on-site for interviews and technical assistance.







State Council on Developmental Disabilities	Ref Doc	Pre-Visit Comments	Site Visit Comments	Post Visit Comments
State Plan is based on public input. Sec.124(d)(1)				

Members of the Compliance/Organizational Structure team include, from the State Councils (Ed Holen - WA, Linda Higgs - WV), P&As (Tim Shaw - NE, Mary Faithful - TX), UCEDDs (George Jesien - AUCD, Michael Gamel-McCormick - DE) and Region VI - Janice Davis. Mary Beth Greene, mgreene@acf.hhs.gov, was ADD staff assigned to the subgroup.

Accountability

Since MTARS was first developed in ADD in the early 1990s, it comprised certain corner-stone concepts, including that a site-visit would look at issues that went beyond the compliance mind-set that focused only on compliance with law and regulation. The compliance view was not abandoned, but was seen as a minimal first step in looking at how well a program was benefiting persons with developmental disabilities. What was included in this concept of “accountability,” however, was not well spelled out, and consequently, it might vary from one MTARS Team to another, depending on what each Team thought a quality program should look like.

Last year Commissioner Morrissey decided that some fundamental changes were needed in the way MTARS were carried out, and a series of work-groups were formed around different MTARS issues. Commissioner Morrissey charged one group of volunteers, chaired by Jane Rhys (Executive Director, Kansas Council) to look at developing guidance for MTARS Teams looking at Accountability. The other members of the workgroup were:

-  Robert Bacon (Executive Director, Iowa UCEDD)
-  Catherine Blakemore (Executive Director, California P&A)
-  Mary Gordon (Executive Director, Nebraska Council)
-  Gloria Krahm (Executive Director, Oregon UCEDD)
-  Anna Lobosco (Deputy Executive Director, New York Council)
-  Shirley Shea (Executive Director, Tennessee P&A)

This work group, consistent with MTARS history, declared compliance to be the minimal level of accountability. Five additional aspects of accountability were identified:

1. data validation

Data validation is something that actually is new to MTARS. MTARS Teams will primarily be concerned with reviewing the data quality control practices that are in place and seeing that the data documentation is well maintained.

2. responsiveness to stakeholders

Responsiveness to stakeholders is something that Congress and ADD have long been concerned about. The management of ADD programs needs to be informed by the wants and needs of persons with developmental disabilities and their families.

3. goals and objectives

Activities in the ADD programs in the States need to be goal and objective oriented. The funding that is made available to ADD programs needs to be maximally focused on the greatest

needs as well as focused on achieving desired outcomes. ADD will be interested both in the process of goal and objective setting as well as in the monitoring of progress toward objectives.

4. program impact

Program Impact is the achievement of ADD programs in a State based on years of effort. It is the consequence of focusing efforts in certain areas year after year without necessarily having a significant measurable impact until finally a break-through occurs. The view of program impact goes beyond annual objectives to focus more on long term goals.

5. collaboration

Collaboration between all three ADD program components in a State (the DD Network) is necessary for achieving effectiveness on behalf of persons with developmental disabilities. Collaboration is envisioned as each of the partners bringing their unique roles and capabilities to the table in order to combine them and coordinate them into a force for systems change. Ideally this collaboration should grow from the planning stage. It is recognized that not all State DD Networks are yet operating at a maximum level of collaboration, but it is hoped that the MTARS process can be a stimulus for change and provide the TA necessary to help guide the DD Network to the next higher level.

The Accountability work group, having identified the five major components of accountability, then went on to create checklists of quality statements within each of the major components. With these checklists in hand, a State that is to be site-visited by an MTARS Team will have a good idea of what the MTARS Team will be looking at. Additionally, the checklist will allow the ADD programs in the State to do a self-assessment and to share it with the MTARS Team, which will use that self-assessment to guide provision of TA as well as to allow the MTARS Team to focus more of its efforts on specific issues where a State may be more in need of attention. Finally, the checklist/self-assessment also allows the MTARS Team to add its own findings and to track issues to ensure that TA is provided where needed. For more information on accountability in the MTARS, contact Jocelin Gridley, jgridley@acf.hhs.gov.

Technical Assistance

As the term Management and Technical Assistance Review System implies, technical assistance has always been a major part of this ADD review process.

Technical assistance is basically a process that brings programs and organizations into compliance or some kind of improvement program. When we're talking about the DD Network, improvement programs includes collaboration, accountability, organizational restructuring, and other processes.

The term technical assistance can seem formal, esoteric, or something "out there." Obtaining TA is (or should be) a natural part of managing an organization. TA can be as simple as staff of one DD network office calling a colleague in another office and asking, "How should I handle this?"

Organizations, however, can also have major TA needs. Within the DD network, such needs can be identified before, during, or after an MTARS visit. TA can be identified in connection with an MTARS visit or entirely independent of one.

ADD's revised MTARS process offers Councils, P&A agencies, and University Centers opportunity to pinpoint what help they need, how they want to enhance their programs, and new programs they want to launch. Understanding the TA needs of grantees can assist ADD staff in selecting MTARS team members and planning interviews and other meetings. Often technical assistance portions of an MTARS can lead to creative solutions in advocacy, capacity building and systemic change. For information on Technical Assistance in MTARS contact Gretchen Menn, gmenn@acf.hhs.gov.

MTARS Processes

An MTARS evaluation is made up of many steps. Below, ADD program specialists discuss two of the steps involved in MTARS. These processes help to set the tone for the rest of the review, and will help the review team focus as they discuss the strengths and weaknesses of the State's programs.

Public Input

One important part of the monitoring process is the Public Forum. The DD Network should plan a public forum to gather comments from the public about the services of the Council, P&A's and the University Center(s). An invitation to the general public to participate in the public forum should be published in a variety of accessible formats including newspapers, newsletters, etc. There are several mechanisms the DD Network can use for obtaining public comments by meeting, teleconference, e-mail, written statements or any combination of these methods. Also, the members of the DD Network are responsible for arranging audio and visual technology at any public meeting site as well as teleconferencing hook-ups and e-mail for individuals. At the public forum the Review Team members listen to all participants and record comments, but do not respond to comments or questions except for purposes of clarification. For information on public input in the MTARS contact Carla Brown, cbrown@acf.hhs.gov

Joint Entrance Meeting

First impressions are lasting impressions and how the MTARS team introduces/presents itself at the joint entrance meeting will set the tone and structure for the MTARS review. Careful pre-visit discussion and planning of the entrance meeting between the Administration on Developmental Disabilities (ADD) staff and the DD program executive directors will culminate in a productive meeting. Part of the pre-visit planning activities for the joint entrance meeting includes agenda development, identification of participants and selection of meeting site.

The joint entrance meeting is a collaborative activity between the Administration on Developmental Disabilities and the three grantee programs: the State Council on Developmental Disabilities, the Protection and Advocacy Program (P&A) and the University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD).

The team leaves it up to the executive directors to coordinate within their respective programs to select participants.

The primary participants from the Council, P&A and UCEDD:

- 🚩 Executive directors
- 🚩 Chairpersons (board of directors, council and advisory board members)
- 🚩 Members (board of directors, council and advisory board members)

- ✚ Program staff from the individual programs
- ✚ State Agency representative, if appropriate
- ✚ Governor's liaison

After introductions, one of the executive directors will have the opportunity to say a few words concerning the MTARS from the program's point of view.

The MTARS team leader will then discuss:

- ✚ the purpose of the MTARS
- ✚ role and responsibilities of MTARS team
- ✚ overview of the process, outcome, report
- ✚ review of the agenda
- ✚ opportunity for questions

Each program grantee will be given the opportunity to give a very brief overview of it's:

- ✚ accomplishments
- ✚ outstanding/successful/creative activities or projects
- ✚ collaborative activities with other local/State groups, agencies and programs
- ✚ program impact on the lives of individuals with developmental disabilities

The overview allows the programs to inform and highlight their contribution toward an individual and collective effort to respond to the needs of individuals with developmental disabilities and their families. For information on the MTARS Joint Entrance Meeting contact Shirley Redmond, sredmond@acf.hhs.gov

Program Progress

Protection and Advocacy Agencies

Ruling in Lewis, et al. v. NM Department of Health et al.

In August, Federal District Court Judge Martha Vazquez ruled that eligible persons with disabilities on waiting lists for community-based services must be served promptly when placement "slots" are available. "This is an important victory for persons with disabilities in New Mexico and possibly across the country", said Jim Jackson, Executive Director of the New Mexico Protection and Advocacy System.

On August 5, 2003 Judge Vazquez granted summary judgment in the Lewis, et al. v. New Mexico Department of Health, et al. lawsuit on behalf of the New Mexico Protection and Advocacy System (P&A). The judge indicated that the relevant facts were not in dispute and that a trial was unnecessary.

The ruling affects persons with developmental disabilities, as well as elderly and otherwise disabled persons, who are on waiting lists for two Medicaid waiver programs that provide home- and community-based services as alternatives to institutional care. There are at least 2,500 people on

waiting lists for each of the programs. Rebecca Shuman, Executive Director of The Arc of New Mexico said, "I believe that this is a huge step forward toward eliminating the waiting lists for people with developmental disabilities and those who are disabled and elderly."

In her 46-page order Judge Vazquez noted that law requires prompt provision of services that are not delayed due to the agency's administrative procedures. Judge Vazquez also ruled that the Department of Health did not always spend all of the money for waiver services that the legislature appropriated for this purpose and that the state did not fill all the slots available. Thus the state failed to meet its legal obligations under the waiver program.

The New Mexico Legislature has appropriated additional funds time after time over the flat budget requests consistently proposed by Governor Johnson during his terms in office. For example: in January 1999, the Administration requested no new dollars, the Legislature appropriated \$6.4 million, and the Department of Health failed to spend \$2.4 million of that appropriation.

P&A and The Arc of New Mexico brought the Lewis case in 1999 with claims under the ADA (Americans with Disabilities Act) and Medicaid law. In November of 2002 most plaintiffs, including those represented by The Arc, were dismissed because they had either died while waiting or were finally placed into services. Judge Vazquez left P&A in the case as the only remaining plaintiff because of their authority under Federal law to represent the needs of individuals with disabilities. Both Jackson and Shuman suggested that planning would be under way shortly to work with the State to implement the decision. For information on Lewis contact the New Mexico P&A: Jim Jackson, Executive Director (505) 256-3100.

P&A Annual Conference

The P&A Annual Conference was held June 8-11, 2004. The turnout was tremendous and comments from participants were positive. For the first time, an all day Governance Institute was held. Governing Board and Advisory Council members came prepared and asked good questions. The Institute allowed for an open atmosphere and provided interactive discussions on real issues in the P&A system. The Administration applauds the P&A Executive Directors for recognizing the importance of the role of governance in the P&A and sending their members to be trained.

This role was also highlighted in the session on the "New Revised MTARS Process" that ADD staff presented on Friday. We encourage you to orient your Board/Advisory Council members on MTARS and share the manual and other materials with them. Advanced preparation with your Chairs and members before an MTARS visit will make the whole process go more smoothly.

For information on P&A programs contact Jacqueline Ezzell, jezzell@acf.hhs.gov

Native American Protection and Advocacy Project

The Native American P&A is sponsoring their 1st Annual Native American Self-Employment Conference for People with Disabilities on July 13, 2004 in Farmington, New Mexico. This conference is a collaborative project with the following co-sponsors: ASSIST! to Independence, Hopi

– Office of Special Needs, Iinah Iliih, Inc. “Precious Life”, Navajo Nation Office of Special Education and Rehabilitation Services, San Juan Center for Independence, Jemez Vocational Rehabilitation, Southern Ute Mountain Department of Social Services and the Zuni Vocational Rehabilitation Services. The topics will include: Independent Living Skills, Benefits, Marketing and Networking, Business Plan, Grant Writing and Website Development.

State Councils on Developmental Disabilities

The Administration on Developmental Disabilities’ 2004 Technical Assistance Institute for State Councils was held June 7 & 8 at the Crystal Gateway Marriott in Crystal City, Virginia. The Institute entitled Councils: Keeping It All In Balance was introduced by Deborah Swingley, Montana Council Executive Director and Chair of the Institute Advisory Committee. The first day featured a keynote speech by John Kemp, nationally renowned speaker on disability, rehabilitation, and health care, and a luncheon delivery on Family Support 360 by ADD Commissioner Dr. Patricia Morrissey. The Institute was attended by 130 participants in addition to NACDD and ADD staff, and was represented by individuals from 47 States and 4 territories.

Participants were treated to presentations and discussions on topics that addressed the varied mandates and responsibilities of Councils. From structuring Council meetings, to Systems Change, to outreach to diverse cultures, the Institute touched on the many challenges faced by today’s State Councils on Developmental Disabilities. The collaborative efforts of ADD and NACDD - the technical assistance contractor – ensured that many technical assistance requests of State Councils were the topics of workgroup sessions. Along with the concurrent sessions, facilitated discussions for Council Members, Staff and Executive Directors allowed open discussion on current topics of interest. The Institute ended with Technical Assistance Advisory Committee Chair Dawn Arsenault from Vermont introducing presentations of Council successes. ADD's Commissioner Morrissey and Joanne Ciani of the Office of Management and Budget (OMB) led a session on OMB's Program Assessment Rating Tool (PART).

ADD would like to thank all participants, presenters and facilitators for an informative 2004 Institute. Information provided in the workshops will be made available through NACDD at a later date.

For more information on Council programs contact Mary Beth Greene at mgreene@acf.hhs.gov.

University Centers for Excellence in Developmental Disabilities Education, Research and Services

UCEDD MTARS Highlights

ADD had a conference call on May 18, 2004 with the 6 UCEDD directors who will be “MTARed” this year. The call was held to help the UCEDD Directors prepare for the MTARS visits. On the call, ADD program specialist Jennifer Johnson reviewed areas that ADD will focus on during the MTARS visit. They included:

- ✚ Outreach and involvement of people with developmental disabilities in UCEDD programs and activities;
- ✚ Examples of Collaborative activities across the State DD Programs;
- ✚ Role of the UCEDD Consumer Advisory Committee in the planning and implementation of the 5 year application; and
- ✚ Technical Assistance to support use of the UCEDD Annual Report Template.

Utah MTARS Site Visit

The Utah MTARS site visit is being held the week of August 15th. The DD Network in Utah is working hard to receive public input for the Public Hearing. The UCEDD is establishing collaboration around the use of technology for communication with their community extensions. The DD Network grantees decided to make this project one of their collaborative efforts. The Utah MTARS site visit team will be linked by 12 extensions around the State to constituents. This videoconferencing will provide an opportunity for the team to hear from a representative cross sample of stakeholders. We will be able to give you feedback in our next ADD Update on its effectiveness.

For more information on UCEDD programs contact Jennifer Johnson at jjohnson1@acf.hhs.gov.

Projects of National Significance

The Program Announcement for Family Support 360 (implementation and planning grants) and youth centers has been published in the Federal Register. The Announcement appears on the ACF Web site http://www.acf.hhs.gov/grants/grants_add.html and ADD's Web site <http://www.acf.dhhs.gov/programs/add/Whats.htm>.

The due date for applications is August 2, 2004. Priority Areas I and II for Family Support 360 both require a letter of designation from the Governor of the applicant's State/Territory. This year, any application submitted without the Governor's letter will be returned to the applicant and not considered in the competition for funding.

Priority III, *Youth Information, Training and Resource Centers Planning Grants*, does not require a letter of designation from the Governor.

If you have questions or need assistance, please e-mail April Myers, amyers@acf.hhs.gov.

Upcoming Events

Youth Conference

July 24-27, 2004- NYLN Conference: The National Leadership Conference for Youth with Disabilities will be held in Washington, DC. The theme for the Conference is Learning, Living, Leading: Youth with Disabilities Continuing the Legacy. Participants will have exciting opportunities

to learn from national disability leaders, public officials, and other young leaders with disabilities from all over the country. Conference goals include helping prepare the next generation of disability leaders and identifying ways to improve policies and supports for young people with disabilities. Most will be between the ages of 18 and 24, however a small number of youth that are 16 or 17 years old will be chosen as “Emerging Leaders.” Details at NYLN web site: <http://www.nyln.org>

Reinventing Quality Conference

August 8- August 10, 2004 at the Doubletree Hotel Philadelphia

For the past four years, the National Association of State Directors of Developmental Disabilities Services has joined with the Research and Training Center on Community Living at the University of Minnesota and the Human Services Research Institute to hold a national conference on Reinventing Quality in developmental disabilities services. Previous conferences have presented the basic principles of quality assurance and improvement, and various approaches to quality at the local, State and Federal levels. This year’s conference will focus on the specifics of the design and implementation of quality initiatives, the nuts and bolts of implementation of quality principles, and specific approaches to making the aspirations of quality assurance and quality improvement a reality.

The title of the 2004 Reinventing Quality Conference is “Developing and Implementing Quality Initiatives to Improve Performance and Enhance Inclusion.” In it participants will explore:

- ✚ specific initiatives that are effective at the local level to increase consumer and family control and input about the quality of services;
- ✚ provider-focused quality assurance initiatives;
- ✚ methods of using information about the quality of services to change and improve services;
- ✚ approaches to collecting, managing, and using information effectively to improve performance;
- ✚ methods of making information available and accessible to consumers and families.